Clinical Standards Advisory Group

Gordon Higginson

The Clinical Standards Advisory Group was established in 1991 under section 62 of the NHS and Community Care Act 1990 as an independent source of advice to United Kingdom health ministers and to the NHS on standards of clinical care for NHS patients and on access and availability of services to them.

Ministerial brief

The group has many projects under way; its first report *Access to and Availability of Specialist Services* was published in response to a request from Mr William Waldegrave, the then secretary of state for health, on behalf of the United Kingdom health ministers, in January 1992: "To advise on access to, and availability of, selected NHS specialist services, with particular reference to the referral of patients across district boundaries to regional and national centres. Your investigations will consider, but not be limited to, the effects of the NHS and Community Care Act 1990 in a representative sample of NHS regions and boards. The four services you have selected are neonatal intensive care; cystic fibrosis; childhood leukaemia; and coronary artery bypass grafting."

As for all its projects, the Clinical Standards Advisory Group appointed a committee to steer the work, chaired in this case by Professor John Richmond. Owing to the disparate nature of the four services, the committee established four working groups (box), which included experts in clinical practice and in public health medicine; they were provided with research support commissioned as appropriate for their purpose.

Clinical Standards Advisory Group's working groups:

<i>Specialist service</i>	<i>Group convenor</i>
Neonatal intensive care	Professor Sir David Hull
Cystic fibrosis	Dr Nuala Sterling
Childhood leukaemia	Dr John Lilleyman
Coronary artery bypass surgery and percutaneous transluminal coronary arthroplasty	Sir Terence English

Regional general managers in England, and the Scottish Office, Welsh Office, and Department of Health and Social Services, Northern Ireland provided information about funding arrangements for the four specialist services before April 1991 and their subsequent approach to contracting. These approaches vary strikingly across the United

Kingdom: six of the 17 regions had fully devolved all four specialties to districts, but otherwise there was no uniform pattern. There exists a mixture of regional and multidistrict purchasing; purchasing by region or by one district on behalf of all districts; and full devolution to districts of one, two, or three of the four specialist services.

Investigations of specialist services

NEONATAL INTENSIVE CARE

Within the range of services provided for the newly born the inquiry into neonatal intensive care was concerned only with intensive care for infants who would die or be left severely damaged without skilled and continuous attention and support. All regional health authorities and the Scottish and Welsh Offices and Department of Health and Social Services, Northern Ireland were asked about their current and future plans for purchasing and providing neonatal intensive care. In 10 regions purchasing of neonatal intensive care had been devolved to district health authorities, in three it had been partially devolved, and in four it was purchased by or on behalf of the regional health authority. More detailed information was obtained by direct inquiries from a sample of purchasers and their main providers from two districts chosen randomly from each region. The survey was conducted by a senior clinical nurse manager with extensive experience in neonatal intensive care. In addition, data previously collected in three health regions were considered.

The survey disclosed that, though few, if any, babies were denied intensive care, a significant number were transferred over some distance. "Contracting" was taking place in a very rudimentary fashion, and measures of cost and quality were not uniform. The group recommended that simple and explicit criteria should be developed nationally for several categories of care by which local purchasers could appraise the neonatal intensive care units with which they wished to contract.

CYSTIC FIBROSIS

Cystic fibrosis is the commonest inherited disease of white people with a frequency of between 1 in 2000 and 1 in 2500 live births. In those with the disease the secretions become sticky, leading to blockage and infection in the lungs and eventually to respiratory failure. The pancreas is also affected, leading to inability to digest food properly. The main therapeutic requirements are chest physiotherapy and preventive and therapeutic antibiotic treatment, coupled with

**University of
Southampton,
Southampton
SO17 1BJ**

Gordon Higginson, vice
chancellor and chairman,
Clinical Standards
Advisory Group

a high nutritional intake and pancreatic enzyme and vitamin supplements.

Cystic fibrosis affects about 6000 people in the United Kingdom. Life expectancy has risen from under one year in 1939 to a 50% survival at 25 years and a 25% survival at 30 years in 1985. This remarkable outcome has altered the disease from one of death in childhood to survival into creative adulthood; by the year 2000 about half the patients will be adults. It has been achieved by the careful application of developing knowledge and of good clinical practice and by cooperation between specialists and primary care and the development of multidisciplinary teams rather than by any one dramatic scientific development. Recently, heart-lung and lung transplantation has proved successful for selected patients, and the future holds the prospect of curative gene therapy.

A survey of specialist services for patients with cystic fibrosis was undertaken in five disparate English regions and in Northern Ireland. The specific aims were to determine access to and availability of NHS specialist services for adults and children with cystic fibrosis; variations within the United Kingdom; the impact of the NHS reforms; and current and future purchasing plans.

The total number of patients with cystic fibrosis in the United Kingdom is rising by 120 a year, mainly in the adult age group. Children born today with cystic fibrosis can expect an average of over 40 years of life, and childhood death from the disease is relatively rare. No significant differences in mortality were found between regions. An average district has 20–28 resident patients with cystic fibrosis, of whom five to ten will be adults; an average region has 350 resident patients with the disease, of whom 150 are adults.

The survey showed that a substantial number of patients receive a poor standard of care, whose main cause seems to lie in lack of knowledge. There is a good degree of clinical consensus on what constitutes acceptable standards of care in cystic fibrosis and on the best means of delivering that care. A high standard of care can be provided with knowledgeable staff, a critical mass of patients, and attention to communication and education in primary and secondary care.

CHILDHOOD LEUKAEMIA

The Medical Research Council's working party on childhood leukaemia began its series of trials in the United Kingdom in 1969, when long term disease free survival was about 25–30%. By 1990 the figure had risen to over 50% and is still rising. The trials cover some 20 major specialist centres treating children with leukaemia in the United Kingdom with a distribution broadly equivalent to NHS regions.

Improved outcome of treatment is associated with increasing advances in and complexity of treatment protocols. Doctors and nurses who care for children with leukaemia need to be very familiar not only with the children's problems but also with the

problems of bone marrow failure induced by chemotherapy, and they need ready access to full support facilities including drug assays, central venous catheters, intravenous antibiotics, and blood products. Such facilities are expensive and their efficient use requires experience, training, and, above all, sufficient familiarity to maintain an appropriate level of expertise. Recognising this, district hospital consultants who previously treated children with leukaemia without reference to special centres, who saw only one or two new patients a year, have largely given up the practice. However, several larger district services offer local treatment to children on a "shared care" basis in collaboration with their regional leukaemia unit.

A survey was undertaken to define the existing organisation of treatment for childhood leukaemia and to see whether the 1990 reforms had disrupted it. Four disparate English regions were chosen, together with Wales and two sparsely populated Scottish health boards. The main questions were whether the NHS reforms had affected either patient referral patterns or resources available for treating childhood leukaemia. There was no evidence from any of the regions surveyed that pre-existing referral patterns are being influenced by any fallout from the internal market, but it is too soon to feel confident that changes will never occur.

One of the most cogent arguments for centralising care of childhood leukaemia and similar rare diseases that are expensive to treat is what might be called the critical mass of experience. For clinical teams to have firsthand knowledge of the less common complications of the various leukaemias or their differing treatments they need to see many patients. Keeping up to date with the latest trial protocols and results requires a continuing and substantial commitment of time. The counter argument in favour of smaller units, apart from the greater convenience for patients which comes from less travel, is that staff tend to have more time per patient, and children thus get a more personalised service. But in the group's view larger centres generally offer greater technical competence and the highest chance of successful treatments. However, the survey results on arrangements for funding treatment of childhood leukaemia gave more immediate cause for concern. Only one major centre in the survey had any clear, guaranteed continuation of current funding through a "regional block contract," and that is seen as an interim measure. All the other units may soon be left to recover costs from local purchasers either by contracts or extra-contractual referrals. It is particularly worrying that most purchaser/provider contracts in the early years will be crude "block" arrangements insensitive to individual "high tech, high cost, low volume" specialties. Part of the reason for the slow progress towards "per patient" contracts is the natural caution of cash limited purchasers when contemplating openended arrangements with all the financial risk on

their side. At present, providers cannot offer them clear assurances on service policy or quality. Moreover, because there are many purchasers each dealing with small numbers of patients (often single individuals), it is difficult to estimate any sensible "average" costs on which to base contracts. In this regard the possibility of centres being nationally recognised, approved, or even accredited to prove clinical services for children with leukaemia might be worth exploring. The Clinical Standards Advisory Group recommended that a national group be set up to recognise and monitor NHS centres treating childhood leukaemia and that such a group should be led by the profession, with input invited from the relevant professional bodies, purchasers, and managers.

CORONARY ARTERY BYPASS GRAFTING

Coronary artery bypass grafting (CABG), developed in the United States in the late 1960s, was not introduced into the United Kingdom until the mid-1970s. By 1982 the rate of surgery (CABG without other procedures) in the United Kingdom was 107 per million population compared with 410 per million in Australia and 770 per million in the United States. In 1981 the rate of surgery varied 12-fold between regions of the United Kingdom, from 21 per million to 263 per million, although these data take no account of patient flows between regions and are therefore only a crude guide to inter-regional differences. A consensus development conference in London in 1984 concluded that a realistic rate for CABG in the United Kingdom should be 300 per million, a target later adopted by the government.

Since the early 1980s the rate of CABG has risen steadily to 212 per million in 1986 and 278 per million in 1990. Though the extent of inter-regional differences has fallen, there were still fivefold differences: 70 per million to 381 per million in 1986 and 97 per million to 466 per million in 1990. The rate in the United Kingdom has continued to lag behind that in most other industrialised countries – for example, in 1990 the rate in Australia was 666 and in the United States was 1760 per million. Although the United Kingdom data refer only to NHS provision, the contribution of private providers, were it to be included, would be unlikely to exceed a further 20% of the total.

It is not possible to consider CABG in isolation from percutaneous transluminal coronary angioplasty (PTCA), the other major revascularisation procedure. First performed in 1977, PTCA became widely established in the United Kingdom during the early 1980s. By 1985, 15 hospitals performed about 1600 angioplasties, a rate of 29 per million population whereas in the United States the rate was 452 per million. The use of the procedure spread rapidly in the United Kingdom during the late 1980s so that by 1991, 53 hospitals (44 NHS hospitals and nine private hospitals) treated 9933 patients (including 12% in private hospitals). Although the rate had risen to 174 per million, the

United Kingdom still lagged far behind other countries – for example, the Netherlands (614 per million) and the United States (1028 per million). A recent report from the Royal College of Physicians of London and the Royal College of Surgeons (England) recommended a rate of 300 per million.

The study was carried out in three English regions and three Scottish health boards, selected according to historical levels of provision, population density, geographical location, and initial types of purchasing contracts. Data for two periods before the NHS reforms were collected for a study of time trends; in all regions data were obtained for the financial years 1987–8, 1989–90, 1991–2, and 1992–3. Huge variations were disclosed in rates of CABG and PTCA among districts, for reasons which are complex and only partially understood; the variations cannot be explained on the basis of the availability of regional services. If purchasers were to continue to buy these services on the basis of historical activity, this inequity of provision would persist. The Department of Health set, in 1986, a national target to be achieved by 1990 of a minimum of 300 CABG procedures per million population.

The rates of CABG and PTCA in the NHS regions studied increased monotonically over the period of this inquiry, but only one region achieved the target of 300 per million, although two others came very close in 1992–3. The rate of increase has fallen as the national target has been approached. In 1991–2 rates of CABG varied ninefold and of PTCA 62-fold between the 42 districts in the study. By 1992–3 the variations had decreased to fivefold and 27-fold respectively.

Many patients endure long waiting times, particularly for CABG. One of the many reasons for this is delays caused by purchasers paying for fewer procedures than cardiologists deem clinically necessary. In this situation, access depends on contracted activity rather than clinical priority.

Conclusions

The four specialist services surveyed have characteristics likely to be found wherever patient numbers are too low and the need for clinical expertise too high for a service to be provided in every general acute hospital. The way in which each such specialist service can develop in harmony with the NHS reforms is bound to reflect its individual needs, as well as the contracting processes under which it is funded. Specific recommendations arising from consideration of each service are set out in the working groups' reports. All four reports have in common five key themes, as follows (box).

Key themes of working groups' findings

- Collection of data
- Access and availability
- Contracting/ commissioning
- Effects of NHS reforms
- Future work

COLLECTION OF DATA

Except for childhood leukaemia, each working group had considerable difficulty in accumulating the information necessary for its survey. The data now collected form a hitherto unavailable basis for later comparative studies. For none of the specialist services was the material in one place. For neonatal intensive care many units had limited or incomplete statistics; for cystic fibrosis the quality of hospital inpatient data was poor and, moreover, virtually no information was available on outpatient and community care, which features so importantly in this lifelong disorder. For CABG and PTCA the general quality of hospital records was also unsatisfactory, and important facts such as waiting times had to be abstracted from individual patients' case notes.

ACCESS AND AVAILABILITY

Specialist services proved to be the most satisfactorily organised for childhood leukaemia in that some 96% of patients were being cared for in main collaborative centres or "shared care" centres. There is evidence that neonatal intensive care services were not meeting the increasing demand: some maternity units seeking to transfer babies found the nearest neonatal intensive care unit full and had to transfer babies excessive distances. Services for cystic fibrosis seemed to be the least satisfactory in that it was not always recognised that good treatment required access to specialist services and there was inadequate access to skilled centres, particularly for adults; poor knowledge of the subject outside the skilled centres; and patchy provision of care by general practitioners and in the community. Much funding for cystic fibrosis services is from charitable sources and therefore insecure, and there are grounds for thinking that some critical staffing posts are vulnerable. The current rates for CABG and PTCA in the United Kingdom are still low compared with those in similar countries. Furthermore, the study disclosed enormous variations in provision across the country.

CONTRACTING/COMMISSIONING

The implementation of the NHS reforms is in its early stages, and the approach to contracting in the periods studied was still underdeveloped. Improvements can be expected as the NHS learns from its experience, and the health departments were already looking at some of the present and potential problems highlighted in the group's report.

Many specialist services are not suited to full devolution of contracting to district health

authorities or to case insensitive block contracts. Providers need contracts that both assure a level of core funding and are responsive to variations in the numbers of patients referred. The forthcoming abolition of regional health authorities will place the responsibility for this supradistrict dimension on the Management Executive's regional offices.

There was a general plea from purchasers and providers for national guidelines for model contracts for the different services. The neonatal intensive care and childhood leukaemia working groups recommend that their specialist centres could best operate and contract if they were subject to some form of nationally agreed accreditation system. This particular proposal would need national multi-disciplinary groups additional to present arrangements, but the merits of the proposals are strong.

EFFECTS OF NHS REFORMS

Much of the data collected relate to the first full year of the NHS reforms, with a snapshot of the position early in the second year. In these early days many of the strengths (and there are many) and weaknesses which the working groups identified in their specialist services predate the NHS reforms. Inevitably anxieties about the future have been expressed by purchasers, providers and "performers" (that is, clinicians), and patients.

In neonatal intensive care there was some reduction of access and more "transfers" in 1991-2 than in the previous year, but this was not attributable to reorganisation. Some patients with cystic fibrosis and parents noted greater difficulty in obtaining supplies of essential medication and had increasing concerns over cost. For childhood leukaemia there had been no apparent change. For CABG/PTCA some providers were beginning to see adverse effects on waiting times and on equity of provision, particularly towards the end of the financial year. However, these observations do not so far indicate significant trends.

FUTURE WORK

A considerable amount of valuable and interesting data has been assembled which justifies regular review and follow up and research is recommended. In two to three years' time the NHS reforms will be more firmly established and valid comparisons will be possible.

This paper is based entirely on the reports prepared by Professor John Richmond and his working group chairmen. The work described, and many of the words used, are theirs, and the author is pleased to acknowledge them.